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Adapting the Family Management Styles Framework (FMSF) for Families Caring for Older Adults with Dementia

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Abstract

This paper presents an adaptation of the Family Management Style Framework (FMSF) -a well-established framework of family response to chronic condition care of children-- to families caring for older adults with dementia. Using the FMSF to better understand how families manage dementia care can provide clinicians with insights on how to work effectively with families. Using data from interviews with eight female caregivers of older adults with dementia this secondary analysis adapts the FMSF, and identifies new dimensions that apply specifically to families caring for older adults with dementia. The discussion draws comparisons between the family management of a child with chronic condition to management of an older adult with dementia. The paper concludes with a discussion of how understanding how families manage care of an older adult with dementia informs assessment for management styles and the tailoring of interventions specific to family, caregiver, and older adult needs.

Keywords

caregiving; dementia; family management; Family Management Styles Framework

Approximately 4.5 million people have dementia, a figure that is expected to more than double to 10.2 million by 2050 (Hebert, Scherr, & Bienias, 2003; Sloane et al., 2002). The progressive decline associated with dementia challenges families as they manage behaviors and care decisions; in fact, family-based care of older adults with severe dementia requires 41.5 hours more of care per week than older adults with normal cognition (Langa et al., 2001). While most caregiving literature focuses on the burden, stress, and negative health effects of providing care for an older adult, there also is evidence that family caregivers may not necessarily view their caregiving in negative ways, but instead conceptualize it as a rewarding experience (Schumacher, Stewart, Archbold, Dodd, & Dibble, 2000). Thus, it may be more clinically relevant to examine both the caregiver's strengths and weaknesses and their perspective about the care they provide (Schumacher et al., 2008). Another limitation of work in this area is that it has focused primarily on the caregiver as the point of

intervention and less on the functioning of the entire family, thereby not recognizing that the family and older adult are part of a larger system of care. Similarly, caregiving intervention research has not simultaneously addressed family, caregiver, and older adult outcomes. This gap indicates the need to move conceptualization beyond the caregiver and to develop interventions that are tailored not only to the needs of the caregiver but also address the needs of the older adult and the extended family (Etters, Goodall, & Harrison, 2008).

Examining how caregivers, families, and older adults manage the demands of dementia can provide useful insights to help health care providers work more effectively with families. The Family Management Style Framework (FMSF) is a well-established framework for the study of family response to chronic condition care of children (Figure 1) (Knafl & Deatrick, 2003). As such, it has been useful for describing the processes families experience, the way they manage care challenges, and family response patterns. The FMSF has three main components: **Definition of the Situation** is how the parents describe important aspects of having a chronically ill child; **Management Behaviors** are the actions parents perform to manage the illness; and **Perceived Consequences** are how the parents describe the impact of the illness on family life. Variation in these components and their underlying dimensions result in patterns of family's response known as **Family Management Styles**. The Management Styles reflect the ease or difficulty the family members experience as they incorporate condition management into family life and the extent to which the family members have common or differing perspectives on the three dimensions. Previous work with families caring for children with chronic illness revealed five management styles: thriving, accommodating, enduring, struggling, and floundering. Knowing a family's management style provides insight into the family's weaknesses and strengths (Knafl & Deatrick, 2003; Knafl et al., 2009; Knafl, Deatrick, & Gallo, 2008).

Studies of families caring for a chronically ill child have identified distinct family patterns in response to the illness. Although it seems logical to assume that families caring for older adults with chronic conditions such as dementia may also have patterns of response, the identification of such patterns has not been addressed thus far. That much said, while the FMSF has primarily been used with the pediatric population, it has been applied to adult populations to frame family management of acutely ill adults who are being withdrawn from life support and to examine the influence of spirituality on family management of Parkinson's disease (Bingham & Habermann, 2006; Wiegand, Deatrick, & Knafl, 2008). These studies found that by adapting and extending the framework, the FMSF could be used to understand family management in these groups as well. The FMSF has been largely used with populations where the chronic illness affects physical health and function, and less so for conditions that affect cognition. Thus, an adaptation of FMSF may prove useful to identify key aspects of caregivers' efforts to incorporate dementia management into everyday life, and to identify family strengths and care challenges to target for intervention. This analysis may also have implications for other families who are experiencing conditions that affect cognition.

This paper presents an adaptation of the FMSF components for families caring for older adults with dementia. Using data from interviews with caregivers of older adults with dementia, we adapted the components of the FMSF by translating the framework for these families, identifying ways the language needed to be adapted and extended, to apply specifically to families caring for older adults with dementia. The paper also compares between the family management of a child with chronic illness and the family management of an older adult with dementia. By adapting the language used in the FMSF, we provide a foundation to guide future work aiming to identify family management styles specific to dementia care. By identifying how a particular family manages care of an older adult with

dementia, it may be possible to assess family management styles and tailor interventions to specific family, caregiver, and older adult needs.

Methods

Design and Settings

This study conducted a secondary analysis of two existing qualitative data sets to adapt the FMSF to apply to families managing care of an older adult with dementia. Qualitative secondary analysis can be a useful mechanism to expand current theory to new populations or phenomena (Hinds, Vogel, & Clarke-Steffen, 1997). This secondary analysis used qualitative content analysis of transcribed interview data from two studies. The first study was conducted in 2005, and aimed to examine how older adults and their family caregivers find and use a specific community-based long-term care service in an urban setting (N=8). The second study conducted in 2006, examining how family caregivers find and use community services in a rural setting (N=17). For the present analyses, we selected a subset of interviews with caregivers who were providing care for an older adult with dementia (N=8, two from the first study and six from the second study). The intent of the analysis was to translate and apply the existing FMSF and adapt components of the framework specific to families caring for older adults with dementia.

Study Procedures

Both studies were approved by the overseeing institutional review board charged with the protection of human subjects. In both studies, participants partook in open-ended interviews focusing on the caregiver's role in the care of their family member, how they obtained needed resources, the role of other family members in day to day care, the typical challenges they faced, and how the older adult ultimately obtained supportive services. The "family" was conceptually defined as how the study participant conceived of it and could include close or distant blood relatives (e.g. parent, cousins, and grandchildren) and non-blood relatives (e.g. in-laws, step or adoptive relatives, and friends). The differences between the interviews for the two studies were that for the urban study the participants focused on how they came to use a comprehensive community-based long-term care service, while for the rural study, interviews focused on how and why caregivers contacted their county-based department of social services.

Sample

Interviews with a total of eight female caregivers were selected for the analysis, two of who were from the dataset from an urban setting in the northeastern United States and six of who were from a rural area in the southern United States. The caregivers were self-identified, determined to be the primary caregiver by the community service providers at the data collection site, or identified by the older adult care recipients. All of the caregivers were female and caring for an older adult with dementia; seven were daughters and one was a grand-daughter. Seven of the participants were African American, one was Caucasian, and they ranged from 24 to 70 years of age. The care recipients ranged in age from 73 to 90 years of age, seven were African American, one was Caucasian. While we did not collect socioeconomic status information, all care recipients were dually eligible for Medicare and Medicaid which suggests that they were of similar, and modest, socioeconomic status.

Data Analysis

In light of the exploratory nature of this work, the goal of analysis was to use the data to adapt the language used in the FMSF to guide future exploration of family management of dementia care. Thus, the FMSF components and dimensions developed by Knafl et al.

(2003) were used to code the interview data. Prior to the start of coding, we preliminarily translated the terms used to describe the FMSF components and dimensions. For example, the original conceptual dimension called “Child’s Identity” (i.e., parents’ view of the child and the extent to which those views focus on illness or normalcy and capabilities or vulnerabilities) was translated to “Older Adult’s Identity” (i.e., caregivers’ view of the older adult and the extent to which those views focus on the illness or normalcy and capabilities or vulnerabilities). This translated version of the FMSF components and dimensions was used to guide the analysis. All of the interviews were coded independently by two members of the study team. Each interview was coded line by line for content that either fit the existing (translated) FMSF components and dimensions; required adaptation of the language used in FMSF; or required new components or dimensions. During this process the coders identified quote examples of instances when the content fit the existing (translated) FMSF components and dimensions as well as those that required adaptation. In those latter instances that data did not fit into the FMSF components or dimensions, the coder highlighted the passage and created notes on how the component or dimension was to be adapted. Through a series of team meetings coded interviews were reviewed to examine these direct quote examples, discuss the examples that did not fit into the FMSF, and consider the adaptations that they illustrated. The goal of these meetings was to achieve consensus between the team members, to be inclusive, and create a comprehensive adaptation of the language used in the FMSF.

Findings

Findings are organized into a description of how the family is defined, and then the three components of **definition of the situation, management behaviors, and perceived consequences**. Each component has dimensions that are described and summarized in Table 1.

Definition of the Family

In the original FMSF, the family includes the child, mother, father and sibling. Analysis of the data in this study revealed that the family consisted of different members, typically an adult daughter caregiver who was either sharing a residence with her parent (the care-recipient) or lived close by to visit on a regular basis. The caregiver typically identified one or more secondary caregivers who were usually siblings. For the most part the care recipient was single either because of separation/divorce or widowhood. At the same time, there was variation in the definition of “family” across the sample. In one case the grand daughter was the primary caregiver and both she and her mother lived with her grandmother, with her aunt providing secondary caregiving. In yet another case, the daughter caregiver lived with her mother, but her nephew lived in the home as well and was available to provide care. In another case the care recipient lived with her daughter and son-in-law but the house was located in close proximity to the care recipient’s daughter, son, and siblings. In this case the daughter functioned as a primary caregiver, but; the extended family was available to provide support as needed.

Definition of the Situation Component

The definition of the situation is the subjective meaning family members attribute to their situation. For caregivers of older adults with dementia, the dimensions include the Older Adult’s Identity, the Illness View, the Management Mindset, and Family Mutuality. The following section provides a description of each of these dimensions.

The Older Adult’s Identity—Analyses revealed that the older adult’s identity is framed by the caregivers’ views of the older adult with dementia and the extent to which those views focus on normalcy (abilities, activities and/or life not compromised by dementia) or

dementia-related deficits (abilities, activities and/or life compromised by dementia and/or related illnesses). The perspective of the older adult's identity is based on a comparison between his/her past personality, function, ability, interests and activities to the current status. For example, in one case, the caregiver noted how unhappy her mother was because she was unable to work and do the things she wanted to do. The caregiver described a tension between what the older adult thinks she can do, and what she can actually do. In another case the family had a history of Alzheimer's disease (the older adult's mother and sister had it) so the daughter was looking for subtle changes in her mother such as repeating words and having difficulty managing finances. The "last straw" was when her mother forgot she was cooking and burned a pot on the stove.

Another aspect of the "Identity" dimension is the caregiver's adjustment of expectations as the dementia progresses and the older adult become more impaired. With increasing impairment, the identity may change as expectations for function are lowered. An example of this is a case of a daughter who was caring for her mother who was bedbound and non-verbal. Over time, the expectation for interaction had changed to the extent that the caregiver described her mother as "being joyful" when her mother opened her eyes when family members spoke to her. The daughter both recognized the many ways her mother's life was compromised, while still identifying some positive moments.

Illness View—Another dimension of the definition of the situation is the caregiver's illness view, meaning the caregiver's belief about the seriousness, disruptiveness, and course of dementia. Study participants described dementia in terms of a long and steady decline leading to death. One caregiver described "when I first came home she went out some, but very little...mother hasn't done much in the last twelve years, she's just constantly, a downward spiral". This quote illustrates the slow, progressive decline associated with dementia. For another caregiver while the illness was viewed as terminal, its seriousness was described in terms of how much medical intervention was needed. For example, the caregiver described, "she has dementia, but she's not on any medications. We just give her like an aspirin, like one today. That's it."

The analysis further revealed that the caregivers viewed dementia within the context of whether they may reach the limit of their abilities to manage the older adult in the home. For some study participants, placement of the older adult in a care facility was not viewed as an option regardless of the circumstances. One caregiver described "I promised [my mother] that she would not go to a rest home as long as I lived. And I have no intention of putting her there. None." Others, however, considered the limitations of their resources and contemplated moving the older adult out of their current living situation to a nursing home. There was variation as to whether the study participants would even consider a nursing home as an option.

Management Mindset—Another dimension of the definition of the situation is the Management Mindset, which is the caregiver's view of the ease or difficulty of carrying out daily care and ability to manage effectively and maintain a balance between independence and safety. There are several adaptations to the FMSF for the management mindset dimension for caregivers of persons with dementia. First, all study participants expressed concerns about the limits of their resources and abilities, noting they were trying to do their best to care for the older adult. The participants also described being constantly concerned with maintaining the balance between promoting the individual's safety and independence while keeping in mind that the older adult may not be able to do many of activities they had assumed responsibility for in the past (e.g., medication management, driving, cooking, being at home alone). They also described daily care in terms of "trial and error", meaning that the caregivers acknowledged their mistakes and indicated that the unpredictable nature of

dementia means that care strategies that work at one point in time may not work as the dementia progresses. The analysis also revealed that caregivers were managing multiple demands simultaneously, which presented a challenge. In five of the eight cases, the participants described that they were providing care for their older parent while having to balance the demands of other family members, such as another ill family member. The caregivers who were managing multiple demands described feelings of stress and difficulty managing their responsibilities. For example, one caregiver described responsibilities related to employment, caring for her mother, and helping her daughter care for her young children because her daughter and son-in-law both traveled frequently for work. The caregiver said she was managing well until her husband became ill, but reported opting for an early retirement in order to fulfill her multiple caregiving responsibilities.

A final aspect of the Management Mindset is a need to accept the older adult's current mental and physical state. The study participants described that they would reflect on how the older adult used to function with a sense of sadness tempered by acceptance. For example, one participant described that everything "mellowed out" when both she and her mother accepted her mother's condition and found new ways to find joy in their day to day life.

Family Mutuality—Another dimension of the definition of the situation is Family Mutuality, which is defined as the caregiver's beliefs about the extent to which he/she has shared or discrepant views with other family members and in some cases with professional care staff regarding the older adult's dementia and his/her own approach to care. Study participants described this mutuality as the combined efforts across family members required to care for an older adult with dementia. While the caregiving roles may not be as socially well defined as those of parent caregivers for a pediatric population, the care situation for older adults with dementia typically has an identified primary caregiver, and other family members who participate in care. For the family caring for an older adult with dementia, mutuality can range from truly shared care, to a primary caregiver providing the bulk of direct care and family members providing occasional help. In one case, the caregiver reported that she provided all of the care and decision making for her mother but also mentioned that she spoke to her brother and sister multiple times during the week to discuss her mother's status. She noted that her brother takes care of her mother's finances so that she can focus on providing direct care to her mother. In another case, the daughter caregiver had no family to help her and when her mother was no longer able to be safe in their home, she moved her to a nursing home. While the mutuality was not necessarily with other family members, this daughter caregiver described that she was in constant contact with the nursing home staff and still very involved in care. This example illustrates that even in the cases when an older adult needs nursing home care, the caregiver can and will stay involved and may develop mutual relationships with the staff.

Management Behaviors Component

The Management Behaviors component of the FMSF is the discrete behavioral accommodations that family members use to manage dementia on a daily basis. It includes the Caregiving Philosophy and the Management Approach.

Caregiving Philosophy—The Caregiving Philosophy is the caregiver's goals, priorities, and values that guide the overall approach to caregiving in the context of dementia care. This philosophy may require the coordination of other family members and is framed by beliefs such as an aversion to nursing home placement and independence, in this context, its overlap with management mindset and family mutuality are evident. One philosophy that study participants described was a need for the family to come together. This need was

especially pertinent for families with a primary caregiver but multiple siblings involved in the decision making for their parent.

Study participants had varying views on whether nursing home placement was an option. Some expressed that they and/or their family had an absolute commitment to not allowing the older adult to go in to a nursing home; others said they would try to care for the older adult in the home for as long as possible, but if the care situation became unsafe, they would consider nursing home placement. Participants also expressed that they wanted to keep the older adult as independent as possible, and wanted to provide everything the older adult needed, implying that nursing home placement was not viewed as a preferable option.

Management Approach—The Management Approach is the caregiver's assessment of the extent to which he/she has developed a routine for providing dementia care on a daily basis and avoiding illness-related problems. Study participants described that their specific Management Approach depended on the extent of the older adult's impairment and while they encouraged the older adult to maintain their normal routine, they had to balance the older adult's comfort with the prevention of complications such as pressure ulcers. For example, in one case the caregiver allowed the older adult to wake up on her own, which meant she rarely was out of bed before late morning. This was described by the caregiver as her attempt to honor the older adult's preferred schedule rather than altering the schedule to be more convenient for the caregiver.

Analyses also revealed that the management approach depended on whether or not the older adult was seeking palliative or hospice care in which case the hospice nurses and providers were very active and involved caregiver in planning, and decision making. The only participant caring for an older adult in hospice described the management approach in the following way:

The nurse comes out sometimes once or twice a week. They provide medicine, some medicines that when she was in the home, that their doctor prescribed.... I don't have to pay for those. They provide, like pull-ups, bedpans. If I, something happens to her, like in the middle of the night, and I call, a nurse comes out.

For one case, the caregiver described a Management Approach that entailed distancing herself from her mother. This caregiver described how her mother's advanced dementia had led to the decision to place her mother in the nursing home. She reported that nurses described her mother as adapting well to the nursing home, but becoming agitated when she visited. The caregiver stated that it pained her, but she had made the decision not to visit her mother because her visits made her mother more upset and confused.

Analyses further revealed that family members caring for older adults with dementia developed an approach for decision making that included strategies for communicating and coordinating decision making with other family members – again similar to the Family Mutuality described earlier. For some caregivers this coordination required frequent contact with their siblings. In one case, the caregiver made decisions about her mother's care on her own but relied on her siblings to help with the financial decisions.

Another management approach that emerged from the analysis was the need to manage resources specifically how the caregiver identifies needs, gathers information, identifies resources, and acquires what is needed including both formal and informal services. For example, in one case the granddaughter caregiver described that she was able to care for her grandmother because she and her mother were living in her grandmother's house and her aunt, who lived nearby, was available as well. The granddaughter stated:

I mean we have to talk to tell who's going to be doing what. Like if I have something to do and my aunt, she'll take up my slack. Or if they got something to do, I'll be here 'cause...I only work on the weekends. And then my mom, she's here in the afternoon. So it just kind of falls into place.

Perceived Consequences Component

The perceived consequences component is the expected family, older adult, and dementia/dementia care outcomes that shape management behaviors and affect subsequent definitions of the situation. The perceived consequences component has two main dimensions, family focus and future expectations.

Family Focus—Study participants described the family focus as being their assessment of the balance between dementia management and other aspects of family life. They described caregiving in terms of their day-to-day life and things that they may not be able to do because of their caregiving responsibilities. One participant described:

When you have a person that's sick to take care of, you don't have a life. ...and it's not like giving up anything, but you do give up. Because things that you would normally do you're not able to do....

In another interview, the participant described the support she received from her siblings, but I also noted she still had given up valued activities saying "I love to go to my Bible study and I love to go to praise service. But if mother's not up to it, then I don't get to go." This narrative suggests that while caregivers may feel supported by the family, they may still struggle with the balance between their caregiving and other aspects of their lives.

Future Expectations—Study participants described future expectations as their assessment of the implications of the dementia, and what the future held for both the older adult and the caregiver within the context of the slow decline associated with dementia. The nature of the dementia trajectory is such that it is expected that the older adult will experience progressive cognitive decline over time until death. This trajectory has major implications for the caregiver's view of the future. Study participants anticipated that the older adult's function would get worse and the caregiver would face increasing demands. Caregivers also anticipated facing the limits of their abilities and having to consider the need for additional support from other family members and formal supportive services, and the possibility of moving the older adult into residential care (e.g. assisted living or nursing home).

Some participants feared they would reach the limits of their abilities. When asked about the future, they described planning to care for the older adult in the home or moving the older adult to a nursing home. This future expectation was most commonly expressed on a continuum. In one case, a granddaughter said that she could not foresee any circumstances for which she, her mother, and her aunt could not manage the care of her grandmother in their home. In another case, a daughter caregiver stated she was trying her best to care for her mother, but if she were unable to care for her safely, she would consider nursing home placement. In a third case, the daughter caregiver decided that she was unable to safely care for her mother (who had dementia and was legally blind) in the home, and had moved her mother to a nursing home. Similarly, one participant described her mother's status as being tied to her own health. She said, "Knock on wood. I'm the only one so far, and I'm hoping nothing happens to me 'cause we would be in bad shape if something happens to me. Mother would have to go in a home."

Discussion

This analysis contributes to what is known about how families manage care for an older adult with dementia, as well as extends the current use of the FMSF. The findings from this study offers several points of discussion and highlights differences between the use of the FMSF to guide research and clinical care for family caring for a chronically ill child and family caring for an older adult with dementia.

When comparing the illness view for family caring for a child to the family caring for an older adult with dementia the long progressive decline with no cure associated with dementia have similarities and differences from the chronically ill child population. The illness view for the chronically ill child typically includes the expectation that the child will be able to maintain some function, become independent, and compensate for his/her illness (Ogle, 2006). This view may be similar, to a limited extent, for families caring for older adults with early stage dementia, when the focus is on preserving function and independence for as long as possible (Murray & Boyd, 2009; Volicer, 2007). Even in this instance however, the illness view for the older adult with dementia changes as the older adult experiences more symptoms and decline and is an expectation for further decline and the family prepares for the older adult to become less independent and require more assistance. This trajectory is not likely similar for families caring for a child with a non-life threatening chronic illness but may be more congruent with families caring for a child at the end of life (Hinds et al., 2005; Liben, Papadatou, & Wolfe, 2008). Further exploration of the similarities of family management for families that are experiencing terminal illness across the lifespan, could further refine the FMSF.

When comparing the caregiving philosophy for family caring for a child to the family caring for an older adult with dementia, the adaptation of the FMSF must account for the involvement of multiple family members in different aspects of care. For example, the pediatric family has clearer and socially defined caregiving roles that, typically involves two parents (Case-Smith, 2004; Knafl & Deatrick, 2003). Analysis for this study revealed that while there was variation in the amount of support a primary caregiver received from other family members, caregiving models involve both individual caregivers as well as those who shared care. Further, within the field of dementia care, the definition of "family" has changed over time to not only include parents, sibling, children, and other blood relatives but also step relatives and friends should include a broader definition of family. By broadening this definition within the FMSF, it would be possible to identify not only the heterogeneity of family management but more interestingly, to explore how similar family management may be across these differing family configurations.

The management approach for family caring for older adults with dementia is very specific to the level of cognitive impairment and how the impairment affects the older adult's function. The management of the pediatric population is similar in this regard, in that it depends on the type and severity of illness (Case-Smith, 2004; Knafl, et al., 2008). These approaches reflect a need for the caregiver to manage information sharing with other family members, including secondary caregivers. In the case of persons with dementia this decision making process may be more complex than what parents' experience with a child however, because the caregiving network is typically more diffuse. Further, the resource management approach depends on several factors, including what informal resources the caregiver and older adult can access, as well as for what formal services the older adult is eligible. While it cannot be determined whether resource management is more or less complicated for the pediatric population with the available data, these differences warrant further investigation.

The perceived consequences for the family caring for a chronically ill child are different from the perceived consequences for the family caring for an older adult with dementia. Family members caring for a child generally have clearly defined boundaries related to where the child lives and who is responsible for providing care; that is, it is assumed that the child will be sharing a residence with the parents and receiving care from them (Kendall & Shelton, 2003). When families are caring for older adults with dementia, however, there can be several housing configurations. For example, a caregiver may move the parent into his/her own home; move the parent to an alternate residence closer to the family member; move in with the older adult, or move the older adult to residential care (e.g., assisted living or nursing home). Another difference is that for family caring for a child there is rarely a limit of the amount or extent care provided in the home, meaning that only in rare circumstance do a families consider institutionalization in group homes or long-term care settings. The typical goal for the family is to successfully “launch” the child. For the family caring for an older adult, however, there is usually an option for nursing home placement, even if the option has been ostensibly dismissed.. The end of caregiving usually happens at the older adult’s death, which is not often the case for pediatric families. Conducting future work to understand the differences in perceived consequences for pediatric families considering group home or long-term care for their child would be a fruitful effort to further explore the intricacies of family management.

While this analysis provides a useful adaptation of the FMSF for families caring for older adults with dementia it is important to note the limitations of this study. First and foremost, this study relied on secondary interview data that were not originally intended for this use. This limitation explains why the data were used to adapt the FMSF but were not extended to elucidate family management styles specific for families caring for older adults with dementia. Also, the sample size for this study was small and was not sufficient for discerning patterns of family management among the data. A logical follow-up to this analysis would be a larger scale study examining family management patterns for families caring for older adults with dementia and the relationship of those patterns to caregiver, care recipient, and family outcomes. Similarly, since the analysis used data from two studies examining community service use, the sample may not reflect the experiences of caregivers of older adults with dementia who are not seeking or using community services. Finally, this analysis provides only the primary caregiver’s perspective, thereby not taking advantage of perspectives of other family members who would have provided more comprehensive view of how the family works together to manage dementia care. Thus, while, it should be noted that a major gap in the literature is that the conceptualization of the family needs to move beyond the caregiver, and this paper presents only the primary caregiver’s perspective, future work taking a more family systems approach and obtaining data from multiple family members (as identified by the primary caregiver or the older adult themselves) would provide further detail and advanced knowledge of families caring for older adults with dementia.

With these limitations in mind, this analysis does, however, contribute to what is known about family management of care for an older adult with dementia. The findings provide the conceptual foundation for future primary data collection exploring and defining family management styles and determining the characteristics of these styles specifically for families caring for older adults with dementia. The adapted version of the FMSF we propose could frame the design of future work by targeting a sample for data collection that would include the primary and secondary caregivers and, care-recipients,. Also, the progressive decline associated with dementia presents the opportunity to longitudinally examine the change in family management as dementia symptoms progress. Tracking families over time could provide useful insights into the key challenges faced by families during the disease trajectory, and possibly indicate key times for intervention.

Further, the dimensions and components identified in this analysis could provide researchers and clinicians with insight into the needs of families caring for older adults with dementia. Future work examining family management of other conditions that affect cognition in both older and younger people could extend the scope of the FMSF beyond dementia to include conditions that affect more than physical health and function. Finally, the FMSF can be used to identify key aspects of caregivers' efforts to incorporate dementia management into everyday life, and to identify family strengths and care challenges to target for intervention. Ongoing work identifying how the families manage care of an older adult with dementia, could potentially improve assessment for family management styles and inform the tailoring of interventions to specific family, caregiver, and older adult needs.

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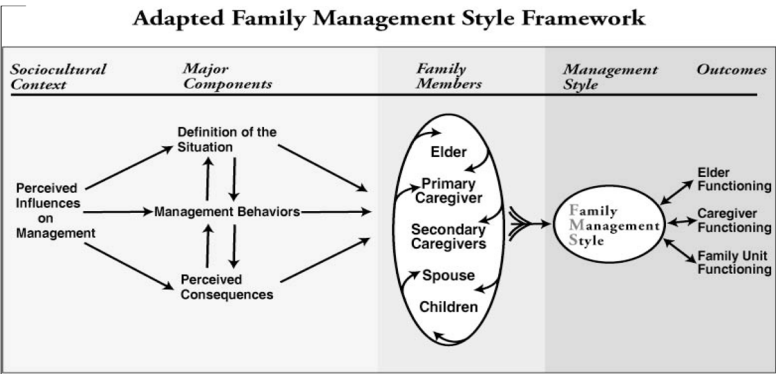


Figure 1. Adapted Family Management Style Framework. Adapted for Families Caring for Older Adults with Dementia.

Table 1
Adaptation of the Family Management Style Framework for Families Caring for Older Adults with Dementia

Original FMSF Component	Original FMSF Dimension	Adapted FMSF Component	Adapted FMSF Dimension	Adaptations and Comparisons Between the Pediatric and Geriatric Populations
Definition of the Situation: Subjective meaning family members attribute to the important elements of their situation		Definition of the Situation: Subjective meaning family members attribute to the important elements of their situation, most notably family life in the context of dementia care.		
	Child's Identity – Parent's view of the child and the extent to which those views focus on illness or normalcy and capabilities or vulnerabilities.		Older Adult's Identity – Caregivers' view of the older adult with dementia and the extent to which those views focus on normalcy (abilities, activities and/or life not compromised by dementia) or dementia-related deficits (abilities, activities and/or life compromised by dementia and/or other illnesses). The older adult's identity is based on a comparison of his/her past personality, function, ability, interests and activities to the current status.	Adaptation: As the older adult becomes more impaired, his/her identity may change as the expectation for function decreases.
	Illness View – Parent's beliefs about the cause, seriousness, predictability, and course of the illness.		Illness View – Caregivers' belief about the seriousness and disruptiveness of dementia. Dementia is viewed as a long and steady decline leading to death.	Adaptations: 1 The seriousness of dementia is determined by the amount of intervention needed. 2 The decline associated with dementia means that caregivers may reach a "limit" to their abilities and there may be some consideration of moving the older adult to a long-term care setting. Comparison: Pediatric – there is hope that the child will be able to maintain some function, become independent, and compensate for his/her illness. Geriatric – with dementia, further decline is expected and the family is preparing for the older adult to become less independent and require more assistance.
	Management Mindset – Parent's views of the ease or difficulty of carrying out the treatment regimen and their ability to manage effectively.		Management Mindset – Caregivers' views of the ease or difficulty of carrying out daily care, their ability to manage effectively, and to maintain a balance between independence and safety.	Adaptations: 1 Caregivers are concerned with the limit to their resources and abilities. 2 Caregivers are concerned about doing the best they can.

Original FMSF Component	Original FMSF Dimension	Adapted FMSF Component	Adapted FMSF Dimension	Adaptations and Comparisons Between the Pediatric and Geriatric Populations
				<p>3 There is a concern for maintaining balance between safety and independence.</p> <p>4 Trial and error are necessary.</p> <p>5 Caregivers manage multiple demands.</p> <p>Comparison: Pediatric – the mindset is the goal of an independent future for the child. Geriatric – the mindset is sustaining the best quality of life.</p>
	Parental Mutuality - Parents' beliefs about the extent to which they have shared or discrepant view of the child, the illness, their parenting philosophy, and their approach to illness management.		Family Mutuality – Caregivers' beliefs about the extent to which they have shared or discrepant views about the older adult, dementia, and approach to care with other family members and in some cases with professional care staff.	<p>Adaptation - Mutuality illustrates the combined efforts required to care for an older adult with dementia.</p>
Management Behaviors – The principles on which parents' management behaviors and abilities are based.		Management Behaviors – The discrete behavioral accommodations that family members use to manage dementia on a daily basis.		
	Parenting Philosophy – Parents' goals, priorities, and values that guide the overall approach and specific strategies for illness management.		Caregiving Philosophy – Caregivers' goals, priorities, and values that guide the overall approach to caregiving in the context of dementia care. May require the coordination of other family member. This philosophy is framed by beliefs such as an aversion to nursing home placement and desire for independence.	<p>Adaptations:</p> <p>1 The family must get organized this is especially pertinent to families with a primary caregiver when others are involved in the decision making.</p> <p>2 Some families had an absolute commitment to not allowing the older adult to go in to a nursing home.</p> <p>3 Some families wanted to maintain the older adult's independence for as long as possible.</p> <p>4 Some families wanted to provide everything the older adult needed.</p> <p>Comparison: Geriatric - adaptation of the FMSF must account for the involvement of multiple family members in different aspects of care.</p>
	Management Approach - Parents' assessment of the extent		Management Approach –Caregivers' assessment of the extent to which they have developed a routine for providing	<p>Adaptations:</p>

Original FMSF Component	Original FMSF Dimension	Adapted FMSF Component	Adapted FMSF Dimension	Adaptations and Comparisons Between the Pediatric and Geriatric Populations
	to which they have developed a routine.		dementia care on a daily basis and for avoiding illness-related problems.	<p>1 Management depends on the level of impairment.</p> <p>2 Management differs if the older adult is receiving palliative or hospice care.</p> <p>3 Management may include being more distant from the older adult.</p> <p>4 Decision Making Approach – how the caregiver communicates and coordinates decision making with other family members.</p> <p>5 Resource Management Approach – how the caregiver identifies needs, gathers information, identifies resources, and acquires what is needed. Caregiver may manage both formal and informal services.</p> <p>Comparison - Geriatric – management of dementia is very specific to the extent of cognitive impairment and how the impairment affects the older adult's function.</p>
Perceived Consequences – The extent to which the parents experience the illness as foreground or background in family life.		Perceived Consequences – The expected family, older adult, and dementia/dementia care outcomes that shape management behaviors and affect subsequent definitions of the situation.		
			<p>Family Focus – Caregiver's assessment of the balance between dementia management and other aspects of family life. This includes demands from multiple generations of the family.</p> <p>Future Expectations – Caregiver's assessment of the implications of dementia, including the implications the slow decline associated with dementia has for the older adult and their family future.</p>	<p>Adaptation: Caregivers described caregiving in terms of the things in their daily life that they may not be able to do because of their caregiving responsibilities.</p>
				<p>Adaptations:</p> <p>1 Dementia trajectory – the expectation is that the older adult will experience progressive cognitive decline over time until death</p> <p>2 Implications for the future – the older adult's function will get worse and the caregiver will have increasing demands.</p> <p>3 The limit of care – Caregivers describe the future in terms of if</p>

Original FMSF Component	Original FMSF Dimension	Adapted FMSF Component	Adapted FMSF Dimension	Adaptations and Comparisons Between the Pediatric and Geriatric Populations
				they plan to care for the older adult in the home, or if the older adult will need to go in to a nursing home. Comparison – Pediatric - only in rare circumstance would a family consider institutionalization.